ABSTRACT

VOIGHT, LAUREN BRITTANY. Exploring Uncertainty Management of Parents of Children with Type 1 Diabetes. (Under the direction of Dr. Lynsey Romo).

Parents of children with type 1 diabetes are likely faced with uncertainty about the illness, which can likely result in favorable or adverse effects. However, little is known about the sources of this uncertainty. Using Uncertainty Management Theory (UMT), this investigation relied on 13 in-depth interviews with parents of children with type 1 diabetes to uncover what type of uncertainty parents experienced during the diagnosis of the disease as well as possible management strategies. This study found that parents experienced medical and social forms of uncertainty. Participants managed this uncertainty through various communication strategies (e.g., seeking medical information, technology, social support). While most participants wanted to reduce the level of uncertainty associated with diagnosis, some would rather maintain uncertainty in order to stay in denial about their child’s illness. In addition to uncovering management strategies, this study recommends that parents and hospital staff implement several measures to address the sources of uncertainty.
Exploring Uncertainty Management of Parents of Children with Type 1 Diabetes

by
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DEDICATION

I dedicate this thesis to my parents, sister, and Matt who always supported me. To my mom who has given her entire life to taking care of my brother and for being a strong and courageous role model. Most of all I dedicate this to my brother Justin who never gives up no matter what.
BIOGRAPHY

The experiences Lauren gained at Florida State University during her undergraduate career have developed her interest in mass media communication studies leading her to the Master of Science in Communication program at North Carolina State University in 2013. During her two years at North Carolina State University, Lauren Voight has had the ability to work with some of the greatest minds in the field of communication. Her graduate school experience has helped her focus on the health communication field and has provided a greater understanding of communication theory and applicable practices. Ms. Voight was offered full time employment after graduation and will continue to work in the health communication field in the spring of 2015.
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Exploring Uncertainty Management of Parents of Children with Type 1 Diabetes

According to the Juvenile Diabetes Research Foundation, 15,000 children are diagnosed with the chronic illness of type 1 diabetes every year (JDRF, 2010). The onset of a child’s chronic sudden illness can be filled with uncertainty for both parents and children (Miller, 2014; Stewart & Mishel, 2000). Uncertainty from a chronic illness can stem from the “individual, the illness and/or the environment created by significant others and health care providers” (Stewart & Mishel, 2000, p. 301). However, although uncertainty is fundamentally communication-oriented and has been extensively examined in the context of a number of illnesses ranging from HIV (Brashers et al., 2003) to cancer in children (Stewart, Mishel, Lynn & Terhorst, 2010), even type 2 diabetes (Middleton, LaVoie & Brown, 2012), little research exists from a health communication perspective that focuses specifically on uncertainty during the diagnosis of type 1 diabetes.

Uncertainty during the diagnosis of type 1 diabetes is critical to understand as the ways in which uncertainty is managed may affect patients’ health and well-being (Brashers, 2001; Mishel, 1990). For instance, although type 1 diabetes is treatable, it is still a chronic illness that requires proper self-management techniques for the rest of the patient’s life. A patients risk of mortality is higher if complications due to uncertainty about the disease arise and diabetes is not managed properly (van der Heide, Uiters, Rademakers, Struijs, Schuit & Baan, 2014).

As the specific uncertainties experienced during the initial diagnosis of type 1 diabetes and the management of this uncertainty are unclear, using Uncertainty Management
Theory (UMT; Brashers, 2001) as a framework, this manuscript seeks to fill this gap through a qualitative examination of the experiences of parents of children with type 1 diabetes. First, the author will present background on type 1 diabetes relating to the diagnosis of children and then review the existing literature on uncertainty experienced in illness as well as diabetes research. Then she will explain the study’s theoretical framework, Uncertainty Management Theory (UMT; Brashers, 2001) and methodology before presenting the results of this qualitative study.

**Type 1 Diabetes**

Type 1 diabetes, also known as juvenile-onset diabetes, is a chronic condition in which the pancreas produces little to no insulin, a hormone needed to convert sugar (glucose) into energy (NCDHHS, 2009). Although type 1 diabetes can be diagnosed at any age, it is one of the most common chronic childhood diseases worldwide (Gale, 2005) and its diagnosis is on the rise (Dabelea, 2009). Type 1 diabetes can be related to the sudden onset of various environmental, genetic, and immune disorders and remains incurable (Atkinson, Eisenbarth & Michels, 2014). It does not disappear over time (Daneman, 2006).

Without proper treatment, an individual with type 1 diabetes will become critically ill and the illness will become life threatening (NCDHHS, 2009). Compounding matters, when the patient is a child, it may be more difficult for the patient to understand information about the illness to begin with, as a child may have limited cognitive capabilities needed to fully comprehend the diagnosis of a disease (Marshall & Lewis, 2014). Therefore, when a child is diagnosed with a disease, the child’s parent or caregiver must learn to understand the
information given regarding medical and management practices (Pleasant, 2014; Rains, 2014). Although disease management skills are imperative for the physical health of the child (Rankin, Heller & Lawton, 2009; van der Heide, 2014), patients and parents are often confronted with a lack of educational resources about type 1 diabetes.

**Lack of educational resources about type 1 diabetes.** While researchers have not explicitly examined sources of uncertainty in type 1 diabetes in child patients and their parents, numerous studies have uncovered that parents and children receive a lack of educational information about type 1 diabetes, particularly during diagnosis. According to the American Diabetes Association (2013), after arriving to a physician’s office or emergency department for the diagnosis of type 1 diabetes, the hospital staff should explain what type 1 diabetes is and how it will affect the child. Then, the family should be instructed how to administer insulin shots and check blood sugar levels on a continuous basis. Next, the family should meet with a dietician to learn how to give the child enough insulin to cover for the food consumed (Summit Medical Group, 2014).

Proper education about a disease is an important aspect for long term management (Neville, 2003). At the time of diagnosis, the patient and their parent may not have any prior knowledge about the disease. The parent may not be able to decipher their child’s level of illness (Macstravic, 1998; Santacroce, 2001) and may be completely unaware of how to manage an inevitable life change. Thus, initial education is generally provided to help the patient and parents be more aware of what is happening in his or her own body and learn how to manage accordingly (Macstravic, 1998).
However, in actuality, not all parents receive this standard of care, and the education can be poor and outdated (Rankin, et al., 2010). Bundesmann and Kaplowitz (2010) found that some diabetic patients did not even remember being instructed to attend educational sessions with a diabetes educator after diagnosis. If patients do not receive information for proper educational practices during the diagnosis stage, then they and their families may be less likely to remember how to manage their disease once they leave the hospital (Bundesmann & Kaplowitz, 2010; Rankin et al., 2010). After all, during diagnosis it may be difficult for the family to fully comprehend all health related information (Pleasant, 2014).

The role of communication may be lacking when it comes to initial diagnosis and the immediate education process of how to manage diabetes. A patient is more likely to repeat a self-care behavior when the provider gives information about the behavior, models the behavior and when the patient sees a diabetes educator (Bundesmann & Kaplowitz, 2010). Like many learned behaviors, a child is more likely to repeat a behavior when it is modeled to the child repeatedly (Bundesmann & Kaplowitz, 2010).

Even when a child feels that they are properly equipped to manage the disease, children and parents are not always informed about what information is most significant to their specific case (Stewart et al., 2010). For example, when a type 1 diabetic individual is faced with inconsistent information from various sources (Rankin et al., 2010) as well as not knowing how to assimilate to new information as progress with the disease develops the individual may be more likely to not practice proper disease management (Bundesmann & Kaplowitz, 2010). Additionally, a lack of educational information distributed during
diagnosis and resulting deficiency in knowledge about disease self-management are likely to result in uncertainty for patients and their parents.

**Uncertainty in Illness**

Many individuals must deal with uncertainty during diagnosis and after diagnosis and uncertainty in illness has been widely researched (e.g., Brashers, 2001; Stewart & Mishel, 2000), including research on how families respond to uncertainty in serious childhood illness. When families are faced with uncertainty in an illness, they shift into a world of unknown (Neville, 2003). Regardless of illness, the change in daily routine that is involved with disease management may cause ambiguity. Indeed, uncertainty is often synonymous with the lack of information about a disease or illness (Ledford et al., 2010). Uncertainty occurs when people are unsure about their environment or events around them and are not confident about a particular situation (Berger & Calabrese, 1975). Brashers (2001) describes uncertainty as a time when the details of a situation are ambiguous and problematic and may cause someone to not be able to understand or define an event or condition. During an illness, people can experience such sources of ambiguity as medical, personal, and social uncertainty (Brashers et al., 2003; Mishel et al., 2009).

**Medical uncertainty.** Medical uncertainty involves uncertainty pertaining to the diagnosis of an illness, the symptom patterns, the implementation of treatment and care as well as the progression and prognosis of the disease (Brashers et al., 2003). Limited research has begun examining the sources of uncertainty in diabetes. However, Middleton, LaVoie and Brown (2012) interviewed type 2 diabetic patients and found that patients experienced
medical uncertainty stemming from “unclear symptom patterns, diagnosis, treatment plan, or prognosis” (p. 594). For instance, Brashers et al. (2003) found that the ambiguity that surrounded the diagnosis of HIV was a main source of uncertainty in the patient. In other words, when the patient was diagnosed with an unknown illness, s/he was confused about what it meant to have HIV and were not certain how to manage the disease (Brashers et al., 2003).

Those with acute and chronic illness face many sources of ambiguity about their health and health related symptoms (Brashers, Hsieh, Neidig & Reynolds, 2006). For instance, Mishel et al. (2009) found that newly diagnosed prostate cancer patients faced uncertainty surrounding the diagnosis of the disease and the possible treatment options. Upon the initial diagnosis of a disease or illness, physicians and staff do not immediately answer all questions of uncertainty that the patient may have. The patient may not understand how to interpret their symptoms and the future that will be based around the decisions regarding the treatment of the disease (Brashers et al., 2006).

Parents may not understand what it means to have a child with a chronic illness or the possible uncertainty based on what may happen in the future, possible treatment options, health risks, the child’s pain level and psychological concerns (Rankin & Haas, 2011). The uncertainty experienced during diagnosis can also be attributed to the length of the perceived illness or how long the child will be in the hospital (Graves & Ware, 1990; Stewart & Mishel, 2000). The uncertainty then continues once the parents bring their child home from the hospital (Mishel, 1983; Stewart & Mishel, 2000). The uncertainty experienced in an
illness by a child and their parent may never completely disappear (Cohen, 1995; Stewart & Mishel, 2000).

**Personal uncertainty.** The personal form of uncertainty involves ambiguity relating to the patient’s self-identity following diagnosis as well as possible financial implications of the illness that can affect the entire family (Carnett, Stone, Scott & Brashers, 2009; Knobloch & Delaney, 2012). When a patient is diagnosed the patient’s identity will become redefined, as will the identity of the family or parent who takes care of the child (Martin, Stone, Scott & Brashers, 2010). The diagnosis of a chronic illness will lead to the patient trying to find meaning in a new way of life, anticipated role changes, conflicting emotions and depression as well as inevitable financial obligations (Martin et al., 2010).

Someone who is diagnosed with a chronic disease will search for meaning in life despite their illness (Martin et al., 2010). Stewart, Mishel, Lynn and Terhorst (2010) found that children undergoing cancer treatment experienced uncertainty in relation to the level of psychological distress caused by an illness where the child had to learn how to self-identify as someone with a disease. After the diagnosis of a chronic illness, the patient will begin to re-identify themselves from a healthy person to someone with a long term disease. This will cause ambiguity in the patient’s life when they try to self-identify as someone who lives with a long term illness (Martin et al., 2010).

After the diagnosis of a chronic illness, the patient will experience multiple sources of uncertainty and will experience emotional changes due to the ambiguity surrounding the disease (Martin et al., 2010). The patient and the family will experience a wide range of
emotions from anxiety to depression and stress (Streisand et al., 2008). These emotional changes are expected after diagnosis and will continue to cause the individual to feel personally unaware of how to manage a life with a chronic illness (Martin et al., 2010).

The onset of a disease can cause uncertainty pertaining to personal matters such as finances. A disease can create a financial burden or added stress for the patient as well as the family with hospital and medication expenses adding up over time (Brashers et al., 2003; Martin et al., 2010). Diabetes (both type 1 and type 2) is the single most expensive chronic disease accounting for $174 billion in healthcare costs as of 2007 (NCDHHS, 2009). Therefore, it is important for the family of a type 1 child to have the ability to plan for a long term disease with a consistent financial requirement. However, the family of the person diagnosed may be unsure of how to pay for the required treatment and are uncertain about how to manage ongoing payments for medication (Brashers et al., 2003; Grawburg, Howe, Worrall & Scarinci, 2013). The financial implications of a chronic illness will lead to further feelings of uncertainty due to the fact that type 1 diabetes is a long term disease that requires a lifetime of purchasing medications (Grawburg et al., 2013).

**Social uncertainty.** Social uncertainty refers to the way in which someone feels or reacts during social interactions after the diagnosis of an illness or during the life course of the illness and how the disclosure of the disease is communicated (Mishel, 1990; Scott, Martin, Stone & Brashers, 2011). In a study of HIV-positive individuals, Brashers et al. (2003) found social aspects of uncertainty related to the communication or disclosure of the disease upon being diagnosed. The diagnosis of a lifelong disease may also have social
perceptions wherein the patient feels that their disease will cause others to judge them based on the stigma surrounding the disease.

Dependent upon the disease, the patient may feel that others treat them differently based on the visible or invisible illness (Donovan, LeFebvre, Tardif, Brown & Love, 2014). For example, some illnesses are invisible (e.g., type 1 diabetes, type 2 diabetes, early stages of cancer) where although the symptoms of the disease are not physically apparent, they still affect every day activities by causing the patient to feel lethargic, irritable or experience internal discomfort (Donovan et al., 2014). Other illnesses are visible where the disease has physical symptoms (e.g., paraplegia). Regardless of the type of illness, having a chronic disease and being different from the general population subjects the person to possible stigmatization compared to those without an illness (Joachim & Acorn, 2000).

Similarly, Defenbaugh (2013) found that revealing a hidden chronic illness can be risky due to the fear of being socially stigmatized for an invisible disease and feel the pressure to validate the illness when they may not physically look sick. Therefore, it may be difficult for the patient and family to find the social support needed when diagnosed with a chronic illness (McMullen & Sigurdson, 2013). In some instances when a patient has disclosed an illness to someone who they valued as a friend, that person may not know how to handle the disclosed information and begin to spend less time around the person diagnosed (Wright & Rains, 2013).

If the person with the illness decides to disclose that they in fact have an illness, the person receiving the information may not know how to react (Brashers et al., 2003). For
instance, in society there are certain illnesses that carry a social stigma (Wright & Rains, 2013). A disease like HIV has the social stigma that the person who contracted the disease may have been promiscuous or brought the disease upon themselves (Miller, 2009). It can be hard for the patient to change the opinion of others around them who already believe something to be true with regard to an illness (Boyle, 2013; Miller 2009).

Uncertainty may act as a barrier to the proper disease self-management in an individual diagnosed with a chronic illness as they may not know how to navigate their illness, identity, or social situation (Brashers et al., 2003; Mishel, 1990). Therefore, it is important to uncover not only the sources of uncertainty experienced but how it is managed.

**Uncertainty Management Theory**

Uncertainty Management Theory (UMT; Brashers, 2001) provides a useful framework for understanding the management of uncertainty related to type 1 diabetes. UMT is a practical theory that has been extensively applied to uncertainty in an illness and can shed light on the importance of uncertainty management for type 1 diabetes in children. While historically uncertainty tends to be thought of as negative, UMT maintains there are many instances where uncertainty can be appraised as neutral, or even positive. When a child is diagnosed with a chronic illness, a parent’s reality becomes full of uncertainty in their personal world. In these circumstances, the parent will evaluate the situation as either positive or negative (Mishel, 1990).

If the situation is deemed negative or dangerous the immediate coping strategy may be to decrease the personal uncertainty felt (Mishel, 1990; Neville, 2003). If people view
uncertainty as negative they tend to reduce it, positive they tend to increase it, and neutral they seek to maintain it (Brashers, 2001). For instance, some parents may seek out relevant information about their child’s illness in order to reduce their uncertainty experienced because the uncertainty is viewed negatively. In other cases, uncertainty can also be viewed as beneficial (Mishel, 1990) wherein not knowing the specifics of a diagnosis is more preferable than actually knowing them, and thus uncertainty is preferable and sought to be maintained (Hogan & Brashers, 2009). In other cases, people seek to increase uncertainty by asking for a second opinion, for example, in order to give themselves hope (Brashers, 2001).

Studying uncertainty from a communication perspective can highlight sources of uncertainty and how it can be managed or not managed through communication (Hogan & Brashers, 2009). Uncertainty experienced during diagnosis of a disease can cause added stress during treatment decision making (Brashers et al., 2006; Shaha, Cox, Talman & Kelly, 2008). After the diagnosis of an illness, individuals may evaluate the level of uncertainty attributed to the illness based on the situation and will decide if the uncertainty is negative, positive or neutral (Neville, 2003). However, limited research has begun examining the sources of uncertainty in type 1 diabetes.

UMT has been used as a theoretical framework in multiple health-related studies (Brashers, 2001). For instance, Brashers et al (2003) interviewed participants who tested positive for HIV about their life experiences and circumstances that caused them to feel uncertain. While some patients would rather decrease the feeling of uncertainty surrounding the disease, many patients learned how to maintain the uncertainty felt about the disease.
(Brashers et al, 2003). Someone with a chronic disease may try to manage their uncertainty by finding a decision alternative equally attractive or unattractive (Brashers, 2001).

Using UMT (Brashers, 2001) as a theoretical framework, Miller (2014) noted that cancer patients do not necessarily want to alleviate all feelings of uncertainty, but have learned to manage the uncertainty through information avoidance in order to restore hope in an unpredictable situation. The feeling of uncertainty can infiltrate multiple facets of a newly diagnosed patient’s everyday life. With disease management, some patients may want to decrease the feeling of uncertainty while some want simply to learn to maintain the uncertainty experienced (Brashers, 2001; Macstravic, 1998). In the face of the challenges of managing type 1 diabetes, diabetic children and their parents likely struggle with uncertainty.

Although identifying and managing “uncertainty in diabetes appears to be of central importance to practitioners and providers, previous work provides only partial evidence as to its underlying sources” (Middleton et al., 2012 p. 7). Little is known about how children and their parents manage the uncertainty experienced during initial diagnosis of type 1 diabetes. An understanding of the uncertainty parents of type 1 diabetic children face will provide healthcare providers, family and friends’ knowledge of potential uncertainty and the ways to manage this uncertainty. As parents are primarily responsible for their young children’s type 1 diabetes management (NCDHHS, 2009; Rankin et al., 2011), the perceptions of parents were solicited in this study. The following research questions were investigated in this investigation:
**RQ 1:** What types of uncertainty do parents of a child with type 1 diabetes report experiencing?

**RQ 2:** How do parents manage this uncertainty?

**Method**

After securing approval from her university Institutional Review Board during the summer of 2014, the author interviewed parents of children with type 1 diabetes to gather information for the present study. The author conducted 13 individual, in-depth, semi-structured interviews with participants. Participants were primarily recruited via a recruitment posting the author submitted to an online type 1 diabetes group. A few participants were recruited via snowball sampling. Potential participants emailed the author to confirm their eligibility and to set up a time for an interview. The participants did not receive any compensation for participating in this study.

**Participants**

The author interviewed 13 parents for this study. All of participants were female and self-identified as Caucasian/White (100%). The mean age of participants was 42 years old (ages ranged from 35-49 years old). Twelve participants were married (93%), and one was divorced (7%) at the time of this study. Five participants worked fulltime, one worked part time and the majority (n=7) were currently unemployed. At the time of diagnosis the children’s ages ranged from (2.5 – 13 years) with the average age of diagnosis approximately at seven years old. Of the participants interviewed, five reported that their child had type 1
diabetes for two years or less at the time of the interview, whereas five had been diagnosed for 3-5 years and three had type 1 diabetes for 6-10 years.

**Procedure**

Interviews ranged from 25–55 minutes ($M = 40$), not including time taken to complete a supplemental demographic questionnaire. Interviews were conducted over the phone because most of the participants and author lived in different geographic regions. After securing participant consent, interviews were audio recorded and transcribed in their entirety by the author. To ensure that privacy of the participants was maintained, the author assigned them each a pseudonym at the onset of the interview. Further, any identifying information such as hometowns, their doctor’s name or specific hospital, was removed from the transcripts.

**Instruments and Analysis**

The author began the interviews with a set of standardized research questions (see appendix). She first asked the participants about their overall experience with their child’s type 1 diabetes and how the participant reacted to the initial diagnosis and the participant’s perception of their child’s reaction. Next, the author asked questions that sought to uncover the uncertainty experienced by the parent and child upon diagnosis of the illness, throughout the disease management process, and how the parent and child were able or unable to manage this uncertainty. Lastly, the author questioned participants about the type of information they received regarding their child’s illness, and from whom. The author also asked follow up questions when appropriate to gain deeper insight on topics, and told
participants they could skip any questions or discontinue the interview at any time. The author stopped interviewing participants once subsequent interviews failed to provide new information and insights, as saturation had occurred (Charmaz, 2006; Morse, 1995).

Using Uncertainty Management Theory (UMT; Brashers, 2001) as a theoretical framework, the author analyzed the transcriptions using a thematic analysis. Uncertainty-management scholars have commonly employed thematic analyses in their health-related research. For instance, Scott et al. (2011) used a thematic analysis to analyze interviews with organ transplant patients pre and post operation about their uncertainty. Bright, Kayes, McCann and McPherson (2013) conducted a thematic analysis in order to shed light on the uncertainty experienced by people after a stroke.

As Braun and Clarke’s six phases of thematic analysis (Braun & Clarke, 2006) has specifically been used to analyze UMT-framed research, (e.g., Bright et al., 2013 and Scott et al., 2011) the author used this approach to identify, analyze, and report patterns. Braun and Clarke’s (2006) six phases include: 1.) familiarizing yourself with your data; 2.) generating initial themes; 3.) searching for themes; 4.) reviewing themes; 5.) defining and naming themes; and 6.) producing the report.

The author began her analysis with the first phase of data familiarity, in which the author transcribed each interview verbatim and then immersed herself in the data by actively reading and re-reading the transcribed interviews in order to search for meanings and patterns among the data (Braun & Clarke, 2006). During the second phase of analysis, generating initial codes, the author began to code aspects of data systematically across the entire set of
data, a stage in which “analysts locate cultural and interpersonal patterns in talk, stories, media content and other narrative texts” (Lindolf & Taylor, 2011, p. 249). The author used the open coding process during the initial coding of the data (Strauss, 1987). As such, the author went through all transcripts line by line in order to organize data based on its meaning (Spiggle, 1994). Then, a constant-comparative method was followed where the author developed themes through an ongoing process of comparing the units of data with each other (Lindlof & Taylor, 2011). As such, the author read through each transcript to find patterns relating to uncertainty and uncertainty management.

The third phase as outlined by Braun and Clarke is searching for themes. In the third phase, the author organized codes into possible themes from the data set. During this phase of inquiry, the construction of themes was not generated from vivid examples alone, but through a thorough, inclusive and comprehensive coding process (Braun & Clarke, 2006). The author incorporated the use of a thematic map that helped organize possible themes, the relationships between themes and the different levels of themes (Braun & Wilkinson, 2003).

The fourth phase is called reviewing the themes, which involves determining if each theme is consistent to the coded extracts of data and the entire data set as a whole. As such, the author examined each theme individually and refined the themes.

The fifth phase is defining and naming themes. In the fifth phase, the author continued an ongoing analysis of the data set to refine and further define each theme and the overall story of the analysis. As such, the author reviewed each theme as it represented the data as a whole and then decided on the themes that best represented the analysis of the data.
The author then named and further defined each theme. For example, the author found that participants experienced medical uncertainty that when further refined included uncertainty about initial symptoms of type 1 diabetes and uncertainty during diagnosis.

The sixth and final phase as outlined by Braun and Clarke (2006) is producing the report. As such, the author re-read all notes collected from the data set and reviewed the final themes to make sure that each theme had enough detailed extracts to produce a scholarly report of the analysis. Then, the author pulled examples from the data set as they illustrated themes. Following data analysis, the author engaged in member checking by emailing all participants from the study to learn whether the findings resonated with participants (Lincoln & Guba, 1985). The 9 participants (69%) who responded indicated that the findings were consistent with their experiences. The author wrote the final report once all six phases of Braun and Clarke’s (2006) thematic analysis were completed.

**Results**

For participants, having a child with type 1 diabetes meant living with and having to manage uncertainty. Participants revealed various sources of uncertainty relating to the diagnosis of type 1 diabetes. Communication-based uncertainty management strategies were also uncovered. Below the author details the types of uncertainty and participants’ uncertainty management strategies.

**Sources of Uncertainty**

Interviews revealed that participants experienced two main forms of uncertainty surrounding their child’s type 1 diabetes diagnosis: medical and social.
Medical uncertainty. Medical uncertainty emerged as a lack of understanding what a disease is, based on unfamiliarity with the disease. This ambiguity can be attributed to the insufficient information presented to patients during diagnosis as well as future ambiguity surrounding the illness.

Pre-diagnosis understanding of type 1 diabetes. Although some participants had heard of type 1 diabetes before diagnosis, most participants had little to no knowledge about the disease. The lack of knowledge about type 1 diabetes was a major form of uncertainty that participants felt inhibited them from fully understanding how to help their child during the initial sign of symptoms. Lizzie’s, 49, daughter who was 13 at the time of the interview and had type 1 diabetes for five years, described her and her husband’s confusion about type 1 diabetes as follows:

We noticed that [our daughter] seemed tired. We had visitors coming in right before Christmas…And we just thought she was tired because we were getting up early and staying up late. You know, and it wasn’t until I went to the refrigerator, and I took out what I used to buy, I don’t do it anymore, but I used to buy these two gallon jugs of apple juice. And it was empty, and I was just shocked and I said to her, “Did you drink all of this?” And she said “Yes.” And I said “When?” And she said, “Well, yesterday and today.” She had been drinking a whole lot and this has lasted probably for about a 10 day period and she said, “Oh I have to go to the bathroom in the middle of the night.” Which she had never done. And it sort of scared me, but I didn’t really know what the signs were for type 1 diabetes. So, I really had absolutely no clue.
Unaware of the possible signs of type 1 diabetes, Lizzie thought that her daughter had strep throat and said that the eventual diagnosis of type 1 diabetes was a “complete shock.” The diagnosis caused Lizzie to experience even more uncertainty because unlike strep throat, type 1 diabetes was completely foreign to her. Anna, 39, whose daughter was six years old and had type 1 diabetes for four years, expressed similar confusion over her daughter’s diagnosis:

My heart stopped and I started crying because I’m thinking, “Wow my life is about to change and how sick is my child?” Ummm, and I’m thinking I don’t know how long were going to be [at the hospital] and I wanted to go get her some stuff at the house and you know I’m not understanding what she can and can’t have and she’s thirsty. I’m giving her no sugar added apple juice, fueling the fire. Yeah, so I was scared because I was not knowledgeable about what it meant.

Anna’s lack of understanding about what type 1 diabetes was made her daughter’s diagnosis of type 1 diabetes more difficult to make sense of. Both Lizzie and Anna were unfamiliar with type 1 diabetes and like many other participants, assumed that the diagnosis would be something easily treatable and not long term. Kristen, 37, whose daughter now 13 had been diagnosed for five years at the time of the interview, also described having little knowledge about the disease before diagnosis:

I didn’t understand what [type 1 diabetes] meant, I had no clue what diabetes was.

We have a history of type 2 diabetes but I didn’t know what type 1 diabetes was at
all. So, I was really scared and unsure I guess because I didn’t know what all it involved. I was told we had to give her shots and stuff I was like what?

In addition to a general lack of awareness about type 1 diabetes, many participants felt uncertainty due to insufficient information that was provided during diagnosis. Anna, whose daughter was diagnosed at two years old felt that the hospital staff did not communicate the diagnosis of the disease in great detail and that:

“I didn’t have a lot of faith in the doctors. I didn’t know how much this would cost, how long we would be here, I didn’t know” as the doctors did not clearly communicate what it meant to have diabetes and that managing type 1 diabetes would be a continuous process.

Similarly, some participants did not feel that the hospital staff provided them with the tools necessary to manage type 1 diabetes. For example, London, 40, whose daughter, now 16 was diagnosed at nine years old, felt that the information provided in the hospital was “too complicated” and that the financial information provided was minimal. London said that “the doctors do not tell you how much managing diabetes costs. It’s very expensive and I had no idea.” Most participants felt that the financial implications of type 1 diabetes was not discussed enough for parents to understand how to plan for the lifetime of medication.

Likewise, Lizzie whose daughter was diagnosed at eight years old at the time of the interview was uncertain about the overall education and nutrition process. Lizzie said that “The information that we received was, in my opinion, not good enough. You know?”
Furthermore, most participants felt that the delivery of diagnosis from the physicians was at times emotionless and did not seem personal to their child, exacerbating their uncertainty during diagnosis. Michelle, 45, whose daughter now 14 and had type 1 diabetes for two years at the time of the interview said that “It didn’t seem like a very big deal that she had been diagnosed with a chronic illness… that emotional support that parents and siblings and patients need [was lacking from the doctors]. Umm, that wasn’t so great.” Most participants felt that some of the most crucial information needed to manage their child’s diabetes was not communicated effectively or not at all by health care professionals. For instance, some participants said that they were not told about night time lows during diagnosis. This information is important because when a child with type 1 diabetes is asleep, their sugar may decline quickly. If the parent is not aware of this element of management there may be severe consequences like a coma or even death if the parent does not check their child’s sugar during the night.

**Future management of type 1 diabetes.** Another form of medical uncertainty that surfaced in the study involved the unknown future that participants felt was associated with the long-term nature of type 1 diabetes. For example, the lack of knowledge with regard to proper management techniques was a major source of uncertainty pertaining to the child’s future. London, 40, who was the primary caregiver of her daughter said that:

I think there could have been a lot more information about how to handle the future. Um, preparing as far as like, for example they didn’t really, I was thinking more type 2 where there’s things she couldn’t eat, and sugar free candy, and sugar you know,
and everyone was coming to visit bringing sugar free stuff, and not really
understanding, basically that sugar free is just as bad as regular candy and they didn’t
explain it well as far as the carbs and carb counting and stuff was just watch what you
eat and there’s sliding scale.

Like London, most participants worried about an unknown future and how type 1
diabetes would alter their child’s future. As Maria, 41, whose son now 12 and had type 1
diabetes for four years at the time of the interview stated, beyond initial information
presented at diagnosis:

There was a lot to learn on the management side of things… He didn’t understand
exactly what was going on, and he would say he kind of thought it was worse than it
was. What would have been fantastic would be classes on how we actually manage it
and how you count carbs how you cook, how you live, but we didn’t get any of that
information…I feel like everything with diabetes is very much a generic approach…

And for the future, I was literally keeping him alive. He would say that a lot, “You’re
literally keeping me alive.”

Most participants did not feel as though they had the communication knowledge to
manage their child’s diabetes, especially in the long term, which is vital for a type 1 diabetic
child. As Ellen, 35, whose son now seven and had type 1 diabetes for almost three years said:

It’s just fear of the now, fear of the future, fear of the heartache and that his life is
going to be changed drastically…He said “I hate myself, I hate my body, I hate
having diabetes” and it just broke my heart.
Ellen said that she felt as though the lack of management techniques that were initially taught after diagnosis left open a lot of room for ambiguity and that “The physicians only addressed the now and did not seem to care to assure us that our child can live a completely normal life.”

Most participants felt that the unknown future a chronic disease presented, resulted in an unimaginable amount of uncertainty. As Kristen, 37, whose daughter was diagnosed at eight years old explained, “I barely remember the whole first year and I was scared to death that I was going to do something wrong.”

Social uncertainty. In addition to medical uncertainty, nearly all participants experienced some form of social uncertainty with respect to not knowing how to deal with or interact with others about their child’s illness. In particular, participants were uncertain how to disclose their child’s illness due to the fear of stigma surrounding type 1 diabetes.

Fear of judgment. Participants felt obligated to tell their friends and family that their child had been diagnosed with type 1 diabetes but were unsure of how to do so. The pressure of exposing their child’s illness caused uncertainty among some of the participants because they did not want others to judge their parenting (or their child) because they had a disease. Many participants said that trying to make other adults understand what type 1 diabetes is was an ongoing learning process. Anna, whose daughter had diabetes for four years at the time of the interview stated that “The general public is uneducated, I had to learn how to explain it.” She continued on to state that other adults will begin to probe the child and ask
them why they are sick or will ask “What’s wrong with you? And you tend to believe that you failed as a parent by giving them too much sugar.” As Anna explained:

When she’s playing with children she’s completely another child, children don’t care. They don’t notice. It’s the adults that say stuff. “What’s that honey? Oh do you have an ouchy?” And then she gets shy about it and then she thinks people are picking on her. So, we’re trying to tackle that as in people just don’t know.

Although type 1 diabetes and type 2 diabetes are caused by different agents, many participants like Ellen, 35, whose son was diagnosed at seven years old at the time of the interview, experienced times when other parents would think that her child was unhealthy, that all she fed her son was junk food and sweets and that he never exercised. Participants who disclosed that their child had type 1 diabetes felt that there was a socially unacceptable stigma around the word “diabetes.” Ellen felt as if other parents judged her when they found out that her son had type 1 diabetes, and did not always know how to manage people’s reactions or potential judgment.

This fear of judgment came from the fact that participants said many in their social circles would confuse type 1 diabetes with type 2 diabetes, which is caused by diet. All participants tried to communicate the difference between type 1 and type 2 diabetes but felt that the stigma surrounding the word “diabetes” led people to believe that their child was unhealthy or never exercised, thus bringing the disease upon themselves and something the child could easily manage by changing eating habits.
Maria, 41, whose son was 12 at the time of the interview and was diagnosed at eight years old, said that the general public, including the school system thought that the child was able to manage the disease on their own by not eating sugar. Maria felt that she had to communicate what it meant for her son to have type 1 diabetes to everyone her son would come into contact with because she feared that if she did not, that her son would not tell others about his disease because he was not sure how someone would react.

Other participants did not know how to help their child adapt to social situations or how to facilitate communication with peers after returning to a previously illness free life. Bonnie, 47, said that her son, 16, was diagnosed at 13 years old and did not realize that he felt differently than other children until he returned to school and had to have someone monitor his sugar and go to the nurse on a daily basis. Bonnie said that her son did not like being called out to go to the nurse because none of the other kids in his class had to do so. Similarly Lilly, 41, whose daughter, 14, was diagnosed at eight years old stated:

Well, you know it’s hard. She’s had a really hard time, she doesn’t like to have to be different than everybody else. And one of the things that’s been a little hard for her you know, especially in grade school she had to check her blood and she had to go to lunch later or she had to go to lunch earlier, she didn’t want to be singled out and you know be different than the rest of the kids.

There are multiple situations in which participants found their child to feel “different” or as “not normal” because of the diagnosis of type 1 diabetes. Regardless of the age of diagnosis, all participants noticed that at some point their child had struggled with feeling
alone or different than the people around them, and participants were not sure how to help their children manage these feelings and potential stigma.

**Uncertainty management strategies**

As Brashers (2001) states, “Communication in uncertainty management follows from appraisals and emotional responses; it encompasses managing uncertainty that is challenging, managing uncertainty that is essential for maintaining hope, learning to live with chronic uncertainty, and managing information problems” (p. 482). In this study, participants employed an assortment of communication techniques to manage uncertainty. As uncertainty tended to be seen as undesirable, most participants attempted to reduce their uncertainty. While less common, a few participants chose to maintain their uncertainty for the fear that reducing their uncertainty could cause anxiety or depression. These participants preferred, temporarily at least, to remain in denial about their child’s type 1 diabetes, and maintained their uncertainty versus attempting to reduce it.

**Reducing uncertainty.** The majority of participants desired to reduce the feeling of uncertainty by seeking medical information, joining support groups, and using innovative technology devices.

**Seeking medical information.** Most participants felt that the feeling of uncertainty was a negative and stressful process and wanted to reduce uncertainty. As Kristen, 37, said, “I did not have any clue as to what diabetes was and the doctors were not helpful enough and caused me to have even more questions.” Participants sought information from physicians and dietary educators in order to reduce their uncertainty about how to properly manage their
child’s type 1 diabetes. As Kimmy, 39, whose son now six years old and was diagnosed at the age of four stated, “You have to seek a lot of information out. You know. It takes a lot of work to see the nutritionist, it’s a lot of appointments and it could be tiring.” At the same time, Kimmy acknowledged that this information reduced her uncertainty.

Most participants were proactive in finding a nurse or physician who was then able to address their primary concerns and help them reduce their uncertainty. As Macey, 48, whose daughter is now 16 and has had diabetes for 10 years stated, after seeking out help from doctors and a 24-hour call line:

…My uncertainty has decreased because we know what we’re doing. We have now a very solid understanding of the disease and what is okay and what’s not okay. And what’s normal. It’s definitely not easy but it’s a manageable thing.

Beyond seeking out assistance from healthcare professionals, other participants turned to the literature to reduce uncertainty. Medical textbooks, hospital flyers, books and pamphlets about type 1 diabetes became of vital importance to participants at during the first year of diagnosis. Most participants felt that by researching more and more information that they were better able to control the management of the disease. As Kimmy, whose daughter had diabetes for two years stated:

I read so much information [about type 1 diabetes] the first six months I don’t think I stopped reading. I read everything from every book I could get my hands on. They sent a nutritionist and set me up with the dietician and the endocrinologist
appointment and they were very accessible but I felt like there was just so much information that I wanted to find out. And I tried to do as much on my own.

**Joining support groups.** Many participants also found that a solid support system was a key element to uncertainty reduction. Support systems largely stemmed from the Juvenile Research Foundation (JDRF) and the families in its network. Most participants said that the first source of information presented to them was a Bag of Hope from JDRF that contained multiple pamphlets, research, and information about type 1 diabetes. Kristen whose daughter now 13 and was diagnosed at seven stated that:

> We had a backpack from JDRF that had a lot of information from like the pink panther book about diabetes and a couple of other books that were for her because she’s so young, like taking diabetes to school and all that. The hospital was really good in helping educate us and then the JDRF foundation actually helped which is why we strongly support them. They actually helped a lot with that whole ordeal… and there was also the JDRF bear from the hospital, she loved him.

Participants also joined JDRF-sponsored support groups to reduce uncertainty. Anna said that she was “completely grateful” to have had the opportunity to have been mentored by another JDRF family. Seeing another family dealing with the same diagnosis three or four years ahead of her helped Anna reduce her uncertainty about what life would be like for her daughter in the future. Similarly, Lilly said, that JDRF “got me contact information of people who are local who have children with type 1 and those people were very helpful and I still talk to them once in a while.”
Turning to technology. Another way that participants were able to reduce the uncertainty of the unknown world of type 1 diabetes was via the use of technology. Technology in this study encompassed all forms of digital media/devices or internet-based software and included the Night Scout, smart phone, Continuous Glucose Monitor (CGM), iPad, laptop and video game consoles. As Anna, whose daughter now six years old, explained:

One of the game changers for us [in terms of reducing uncertainty] has been Night Scout. There are smart parents and people with type 1 who have taken matters into their own hands and come up with some programs that work on an Android phone where the monitors transmitter connects to an Android cellphone and in about two hours set up, these people who are on the Facebook group CGM in the cloud, and what it does is it uploads the CGM information to the cloud so anyone in the world from a website can pull their child’s blood sugar real time.

Anna was able to alert her daughter’s teacher of an extreme low in blood sugar because the device allowed her to see her daughter’s blood sugar constantly online when she is not with her daughter. Although her daughter or the teacher may not hear the alert, Anna was able to text her teacher because she was also able to see her daughter’s blood sugar level. When asked, all participants said that their child also used some type of technology on a daily basis including: smart phone, laptop, iPad and video game consoles. These technologies helped participants reduce the uncertainty felt due to the ease of access to technology that
was able to monitor their child’s diabetes. Michelle, 45, whose daughter was 14 and had type 1 diabetes for two years at the time of the interview stated that:

For managing diabetes, I think it’s the smartphone over anything else, she has an iPod touch that she sometimes keeps track of, and she feels familiar with apps and the using of apps, and we have the ipad at home too, she seems to gravitate towards that type of size and the pump is close to that size or smaller and her CGM is small. We’re really excited about the bionic pancreas and the idea of the use of the smart phone.

The technologies used to manage type 1 diabetes helped reduce the levels of uncertainty participants felt. These technologies were able to help participants monitor their child’s blood levels and see how their child’s body reacted to the levels of insulin throughout the day. This control via technology alleviated some of the medical uncertainty participants experienced when they were not able to be with their child at all times.

**Maintaining uncertainty.** Although most participants wanted to reduce the level of uncertainty they felt, some participants said that they would rather maintain uncertainty in various situations. Some participants reported that when they began to notice that something was wrong with their child, they entered a state of denial instead of seeking out a diabetes diagnosis. They preferred not to know versus having to deal with a negative certainty.

**Experiencing denial.** While the majority of participants took immediate action and brought their child to the hospital to possibly be diagnosed with an illness, some entered into a feeling of denial to maintain uncertainty. They did not want to acknowledge there was
something wrong with their child, and they wanted to avoid the possibility of experiencing depression. Jamie, 38, whose son, five, and was diagnosed at four said that:

Okay, so [the preschool] calls me on a Friday and they noticed that he had been drinking excessively and urinating. And I hadn’t noticed it. The [teacher] says, “All right, I’m not trying to scare you but I just happen to know that, that could be a sign of diabetes. We’ve been tracking it.” She and the assistant teacher had been tracking it! So, that weekend… my friend came over, a nurse, and was like “Yeah, we need to go to the doctor.” And she was like, “No let’s go today.” So I was like, “Okay,” so I took him the next day and we went in. I didn’t realize this was hospital-like. So we went to the doctor, the primary doctor. And they did a urinary test. And he said, um, “It came back with whatever it, I don’t even want to say the word because it’s only a possibility but I want you to see a pediatric endocrinologist.” So I was like okay I’m still thinking nothing of it. Um, so the next day before I could even call the endocrinologist the doctor called back and said “I already called the endocrinologist and he has diabetes and we need to see him as an emergency patient.” And I was like “What?” And I still didn’t get it, really… I didn’t really know anything about it and had brushed things under the rug.

Because Jamie feared that her child would be chronically ill for the rest of his life, she did not seek out an immediate diagnosis. Like Jamie, some other participants were in denial that their child could have a chronic illness and chose to remain uncertain about the fact that something could be wrong with their child. Participants felt as if there were no way that there
child could be sick because the child either came from a healthy family or that their child had never been sick. For instance, Kimmy said she was in complete denial when the beginning stages of type 1 diabetes began to surface. She initially noticed signs of binge water drinking and rapid weight loss but insisted that her son was a growing boy and that is what caused the symptoms. She did not want her son to experience a chronic illness and had no clue as to what type 1 diabetes even was:

I remember he was young but he wasn’t feeling good, he just was lethargic I remember he would sleep every day and nap and had kind of been going on and he was playful, your typical boy, but he required a lot of rest. And I was saying “Oh he’s just growing, that must be it.”

Much like Kimmy and Jamie, Lilly whose daughter was diagnosed eight and was now thirteen also felt that there was no way that her daughter could have type 1 diabetes. Lilly found herself in a state of denial when her daughter became more and more sick. As such, Lilly explained that:

I noticed that she was hungry more and that she was thirsty more and it even crossed my mind that could she be diabetic or something? Like that crossed my mind a couple of times. And I was thinking oh no, she’s not over weight and she’s growing because she’s eight years old she would grow, she grew like three or four inches every year, so I thought that she was just growing. Um, and it wasn’t actually, which I feel like a horrible mother telling you this, but it wasn’t until she was actually throwing up sick
for 24 hours that I finally took her to the hospital because she wasn’t getting any better and that’s when she was diagnosed.

A few participants would rather remain uncertain about the initial cause of their child’s symptoms because they would rather believe that their child had a much more minor illness than come to terms with their child’s chronic disease symptoms.

**Discussion**

Through in-depth interviews of 13 parents of children with type 1 diabetes, this investigation sheds light on parental uncertainty about type 1 diabetes, finding that participants faced medical and social forms of uncertainty. Participants heavily relied on communication strategies to manage this uncertainty. Participants who viewed uncertainty as negative looked to reduce uncertainty via seeking medical information, implementing technology, and relying on social support groups. Other parents who perceived uncertainty to be more neutral sought to maintain uncertainty by living in denial and not coming to terms with the fact that their child could have a chronic illness. Although uncertainty has been studied in other illnesses, and can influence the experience of a type 1 diabetic, very little research has been conducted on type 1 diabetes specifically. Thus, there is a pressing need to understand how the uncertainty accompanying diabetes is manifested and can be managed by a caregiver. Without this awareness, parents may struggle to maintain proper management of their child.

The results aligned with previous research (Brashers et al., 2003; Middleton, LaVoie & Brown, 2012) and suggest the importance of communication during the diagnosis of a
chronic illness. Had the diagnosis of type 1 diabetes been communicated to the family in a way that the parent understood the information, it is likely that the level of uncertainty experienced during diagnosis may have decreased. Results suggest that the uncertainty experienced varied based on the level of psychological stress or previous experience of disease management, thus leading to the ways in which this uncertainty was managed.

By leaning to manage uncertainty either by reducing or maintaining the feeling of uncertainty, participants learned how to cope with the diagnosis of a chronic illness. Successful management of uncertainty seemed to help parents find a way to better manage a life with type 1 diabetes. After analyzing data, three main management strategies emerged. This study indicates that the use of technology, social support, and financial information can serve an important role in helping providers and hospitals better support families with type 1 diabetes. Below, practical ways to employ the uncertainty management strategies are described.

**Technology.** This study supported the notion that during the diagnosis of type 1 diabetes, there is a lack of organization for the overwhelming amount of information distributed to parents (Nordfeldt, Hanberger, & Bertero, 2010; Rankin et al., 2011). The child, parents and family members are filled with questions about type 1 diabetes: what does it mean to have type 1 diabetes and what do we do now? The current solution to this problem is for the hospital staff to give parents an overabundance of paperwork to sift through. However, the experiences of participants in this study suggest that the hospital staff should educate patients and parents about type 1 diabetes via technology. The implementation of
technology to teach patients about their illness can provide possible answers to families’ questions (Nordfeldt, Hanberger, & Bertero, 2010). For the purpose of this study, the forms of technology that should be implemented include digital media and devices, as well as internet-based software.

**Digital media.** Most hospitals do not use technology to teach the child and family about type 1 diabetes. However, multiple forms of technology could be used to educate families about chronic illness (Nordfeldt, Hanberger & Bertero, 2010). For example, during the stay at the hospital each family should be given an Ipad or tablet that would contain files of information for parents to read about what type 1 diabetes is as well as a way to send the information to the parent’s personal email account. The tablet would be accessible both online and offline, thus the location and internet accessibility would not create a barrier to the information (Thompson, Baranowski & Buday, 2010). While the documents of reading material are accessible online, the parent should have the ability to email the information to a personal email account if they choose to do so. The information should also be easily downloaded to the parents’ home laptop, tablet or computer to be used at their convenience (Nordfeldt, Hanberger & Bertero, 2010).

The tablet should also contain carbohydrate and calorie calculators to teach the family how to give the correct amount of insulin to their child for the amount of food consumed. The use of these forms of digital media can help reduce the uncertainty experienced with relation to the lack of educational information currently received during diagnosis. These devices will force the doctor and family to work together when learning disease self-
management. This information will also help parents once they return home and do not have the ease of access to the doctor. When a child is diagnosed with a chronic disease at a young age they do not know how to apply the new management strategies to everyday life (Marshall & Lewis, 2014). Tablets could help ease uncertainty.

**Type 1 diabetes games and applications.** In addition, smart phone applications and games for video consoles should be played at the hospital during the time of diagnosis. An educational game that walks the child through the disease and explains what is happening in their body at the time of diagnosis may better able the patient to adapt to having type 1 diabetes. Children and parents may be more likely to play a video game that teaches about their diagnosis rather than read through hospital documents. The gamming device and the smart phone applications (games) should be accessible offline. Although type 1 diabetes applications do exist, such as Glucose Buddy Diabetes Helper, Packy & Marlon and Captain Novolin, (Shaffer, Squire, Halverson & Gee, 2004) these applications and gaming devices are not typically used in the hospital and the hospital staff does not work with the child via technology to help them understand how to manage the disease.

Video games that are based on a health topic employ the use of entertainment in order to promote behavior change (Thompson, Baranowski & Buday, 2010). Health related video games use self-learning techniques that encourage the player, in this case the child, to learn through experimentation on a digital platform (Shaffer, Squire, Halverson & Gee, 2004). The video game would have the child first set a goal (e.g. diabetes management) followed by goal monitoring and problem solving (Thompson, Baranowski & Buday, 2010). The behavior
changes, such as goal setting, that are employed in the video game will encourage the child to make the same behavior changes in their daily routine (diabetes self-management) (Thompson, Baranowski & Buday, 2010).

For example, Captain Novolin is a video game in which the protagonist, Captain Novolin, has type 1 diabetes and takes an entertainment approach to teaching children with type 1 diabetes how to self-manage (DeShazo, Harris & Pratt, 2010). The game shows the player what foods should be eaten and which should be avoided via the use of aliens versus the superhero (good versus bad). Evaluations of type 1 diabetes video games have shown through the use of situational problem-solving methods to teach diet, exercise, self-monitored blood glucose levels and medication adherence have shown positive outcomes in knowledge disease management and clinical outcomes (DeShazo, Harris & Pratt, 2010). Therefore, smart phone applications and gaming devices should be used during diagnosis in an effort to help the child understand how to manage their diabetes via the various platforms of technology.

**Social support groups.** This investigation also recommends that all providers are referred to social support groups during diagnosis. When a patient is diagnosed with type 1 diabetes, the hospital staff is supposed to give the family support information from JDRF as well as a way to get in contact with the JDRF support system. However, not all families are given the information for support groups that are needed. Middleton, LaVoie and Brown (2012) found that when someone was diagnosed with type 2 diabetes, one of the reasons that
some patients were not able to adapt to educational information about the disease was due to the lack of social support.

Research suggests that when a child is diagnosed with an illness, parents need support from others in order to manage feelings of uncertainty surrounding the diagnosis (Wright & Rains, 2013). Therefore, JDRF should send representatives to the hospital when a child is diagnosed to provide the initial communication support for the family. One of the greatest causes of uncertainty as revealed by the results of this investigation is that at times parents felt alone and did not know where to turn. Although some parents knew about JDRF through pamphlets and contact information, the information of some parents during diagnosis was not given directly to JDRF and the family was not contacted as a result. If JDRF implemented volunteers to contact patients upon diagnosis, the family would be able to initiate immediate support to answer questions which would help manage uncertainty due to diagnosis.

Although JDRF is a national organization, they are not able to reach every child that is diagnosed. Therefore, JDRF volunteers should help organize online video chat support groups for parents who have questions about type 1 diabetes. This investigation uncovered that parents need support during the diagnosis of type 1 diabetes and need to have the personal connection to someone who can answer their questions during a time that is surrounded by uncertainty.

Middleton, LaVoie and Brown (2012) found that patients with type 2 diabetes managed uncertainty experienced during diagnosis through constant communication with family and friends. Likewise, this investigation aligns with this management strategy but also
expands on the importance of social support from experts. One way that parents can better manage their child’s diabetes is to have the ability to communicate with diabetes experts on a 24/7 basis. While some parents knew that a 24/7 hotline existed from their own research, not all parents were provided with this information. Parents should be provided with a FAQ handout that addresses urgent questions that parents go through on a daily basis. If parents are more aware of the information provided to them about type 1 diabetes, they may be more able to manage medical forms of uncertainty.

Parents should also be given guidelines on how to disclose type 1 diabetes to family and friends. Due to the fact that stigma surrounds chronic illness (Rankin et al., 2011) parents would benefit from sample scripts and possible questions that someone unknown to type 1 diabetes may ask. This information could better help parents manage the social uncertainty surrounding social situations.

**Financial information.** Research suggests that following the diagnosis of a chronic illness, financial uncertainty will become prevalent (Carnett et al., 2009; Knobloch & Delaney, 2012). Participants resonated with the fact that upon diagnosis, parents are unaware of how much type 1 diabetes will cost. When a child is diagnosed with type 1 diabetes, the hospital staff should give the family a financial guideline that shows each aspect of the medication (e.g., Insulin, test strips, blood sugar checker) and an average of how much it will cost. After all, in order for the child with type 1 diabetes to live a healthy life, the parent has to purchase the proper medication.
However, parents need the opportunity to plan how much type 1 diabetes will cost financially and adjust their family budget accordingly. Although the medication is mandatory for survival, it would help the family of the newly diagnosed to understand the cost and possible options for payment plans and insurance adjustments. Parents should also be given contact information for a local pharmacist who can better explain how each part of the insulin shot or blood sugar checker work and the monthly cost for refills. This would help reduce the uncertainty experienced during diagnosis with relation to financial obligations.

Limitations and Future Directions

This study has several limitations. Participants were initially recruited via an online support group whose members were predominately female and of white backgrounds. Thus, this study had a lack of age, sex, and diversity among participants. It is also important to note that the results may reflect a subset of the population because all participants were of similar backgrounds. For instance, the health literacy level may be higher among the participants in this study who were of a predominately white and educated background (Osborn, Cavanaugh, Wallston & Rothman, 2010). Participants in this study may have been better able to implement technology as a management strategy due to the fact that they were able to purchase healthcare related devices (e.g., gaming systems, tablets, smart phones) (Edege, 2006).

It is uncertain whether members of other online support groups or a more diverse sampling of participants would result in varied findings. The fact that all participants from this study were recruited via an online posting may have some correlation to the finding of
technology importance. Also, the study relies on the experience of 13 individuals. Although the sample size was small, the author reached saturation at interview nine and conducted four more interviews to make sure that the information found was consistent with previous interviews (Lindolf & Taylor, 2011). Additionally, each in-depth interview lasted an average of 40 minutes. Another limitation is that interviews were conducted over the phone and participants may have revealed more detail in person; however, participants may have been more open about their experiences as the phone may have made them feel more comfortable and that their interviews were completely anonymous (Lindolf & Taylor, 2011).

Several opportunities exist for future research. First, the sources of uncertainty and the ways in which uncertainty is managed is of vital importance. If scholars conducted a similar study, they could determine patterns of not just how uncertainty is managed, but when the stages in which uncertainty is managed from initial diagnosis to the years following. Third, scholars could interview children with type 1 diabetes to gain their perspective about the uncertainty experienced during diagnosis and how they managed that uncertainty. Another study could follow up with quantitative research by creating a survey that inquired about the uncertainty experienced during diagnosis and how it is managed in order to uncover potential relationships between hospital diagnosis experience and the level of uncertainty. Lastly, a study could explicitly explore what technologies could help children and parents better manage uncertainty surrounding type 1 diabetes.
Conclusion

This study provides valuable insight into the uncertainty experienced by parents during the diagnosis of type 1 diabetes and how uncertainty was managed. Results suggest that uncertainty sometimes enacted as a protective strategy to avoid psychological stress and an unknown future. The practical results offer several valuable areas of research on how communication plays a critical role in the way that parents manage uncertainty during the diagnosis of type 1 diabetes and contributing factors to the cause of uncertainty. This investigation sheds light on possible management strategies for how parents cope with the uncertainty during the diagnosis of type 1 diabetes. This investigation and its results can be applied to the diagnosis of a chronic illness. Regardless of illness, the diagnosis of a chronic disease will likely cause someone to experience uncertainty (Brashers et al., 2003, Mishel, 1990). Uncertainty does not simply disappear, instead it must be managed. The results of this investigation highlight the ways in which parents of children who are diagnosed with a disease can manage the uncertainty experienced.

This investigation also applied the use of UMT to the new realm of the diagnosis of type 1 diabetes. This study affirms the fact that someone who experiences uncertainty does not necessarily want to reduce the feeling of ambiguity, but may rather maintain the level of ambiguity. The way that communication is used to manage uncertainty can help someone maintain or reduce their uncertainty (Brashers, 2001). Due to the fact that type 1 diabetes is a chronic long term illness, the management strategies implemented in this study are valuable for families and providers to rely on during and after diagnosis to help manage uncertainty.
References


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Appendix A

Interview Questions

*First, a few background questions:*

1. Where are you from originally?
2. What is your line of work?
3. How old are you?
4. How old is your child who has type 1 diabetes?
5. How old was your child when he/she was originally diagnosed? (Age, year etc.)
   How does your child manage his/her diabetes medically? (Ex: Pump, shots etc.)

*Now I am going to ask questions about your initial experience during diagnosis:*

6. When did you first begin to notice signs that your child might have type 1 diabetes?
7. What was going through your mind at that time in terms of what you thought was wrong with him or her?
8. To what extent did you feel any uncertainty during this time?
9. Please walk me through your experience from when you suspected something was wrong and you got that original diagnosis; Tell me about that initial diagnosis visit when you found out that your child had type 1 diabetes.
10. Can you describe your first reaction when you heard that your child type 1?
11. What type of information or advice were you given in regards to your child’s type 1 diagnosis?
12. What things were you uncertain about during that initial diagnosis?
Follow up questions (if not answered by #12):

Were you able to manage or alter that feeling of uncertainty? Why or why not?

What barriers, if any, stood in the way of uncertainty management?

What role did the doctor or his or her staff play in helping you manage uncertainty?

13. What was your child uncertain about following that original diagnosis?

Follow up questions (if not answered by #13):

How did your child manage their experience? Do you remember any specific example of how your child dealt with the uncertainty?

To what extent did the information come in? (paper, electronically etc.)

Now I am going to ask questions about your experience in regards to the hospital/doctor’s office:

14. Please describe the education process when learning how to manage the disease. Explain.

15. Did your child understand what type 1 diabetes was or did you have to explain to them what type 1 was?

16. Please describe the overall hospital experience during your initial visit? Explain.

Now I am going to ask questions about any communication that took place

17. What advice from the doctor helped you deal with the uncertainties you had? What advice was not helpful?

18. Please describe for me your experience with your child’s type 1 diabetes during your first week home.
19. What do you think could help you manage the first week experience?

    Follow up: Were these new changes the same for your child or did they also deal with different changes? (i.e.: school related practices)

20. What is your child’s life like now with type 1 diabetes compared to before?

21. How has your communication changed with your child since the initial diagnosis of type 1 diabetes?

22. Do you teach your child’s teacher about type 1 diabetes? Were they open to learning?

    Now I am going to ask questions about your current diabetes management practices:

23. In your opinion, how would you describe your current communication with your doctor during visits?

24. Has the uncertainty you feel in regards to diabetes increased or decreased since diagnosis?

25. People with diabetes face many issues in their day to day lives. To what extent do you feel that your child interacts in certain social situations differently because they have type 1 diabetes? Please explain.

26. To what extent do you feel that self-care management is a process that your child must learn in order to continue proper management of their disease?

27. What times have you sought information and where have you turned? Have you ever found yourself avoiding any health information?
Now, questions regarding educational materials:

28. What tools does your child use to manage their type 1 diabetes? Do you use the same devices or are there extra tools that help you manage their diabetes each day?

29. If you could change one thing about the way your doctor communicates to you about the disease, what would it be? Explain.

Future trends:

30. Have there been any instances where you found yourself more likely to want to remain uncertain about something regarding your child’s diabetes? Why. Explain.

31. Are there any barriers that you feel cause you to not know how to properly manage your child’s diabetes?

   Follow up: Do you feel that these barriers could be reduced if not eliminated? How so?

32. What could your doctor do to improve communication about type 1? What could you do?

33. What devices or technology do you think would help better manage your child’s type 1 diabetes, if any?

34. Do you feel that one type of technology works better than another? (Ex: smart phone vs. tablet).

35. Does your child interact with any smart phone applications or videogames? Explain.

   Follow up: Are any of them related to type 1 diabetes?
36. With the advancement regarding insulin and blood glucose administration, do you feel that new devices could enhance your child’s day to day life?

Role Play

37. Let’s pretend for a minute that I am your daughter/son who has type 1 diabetes. I’m going to give you a scenario and I want you to talk to me the same way you would your own child.

“Mommy/Daddy, tomorrow at school the nurse won’t be there and I’ll have to give myself a shot. What do I need to do?”

38. If your child is on their own, do you feel that they are equipped to take care of themselves? Explain.

39. Would you mind putting me in touch with any other parents or caregivers of children with type 1 diabetes?

40. Thank you so much for your help!